

# **Appendixes for Transition Care for Children With Special Health Needs**

Appendix A:	Literature Search Strategies
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# Appendix A: Literature Search Strategies

**Table A-1: Search strategy and results from PubMed (last updated 9/5/2013)**

Search terms		Search results
#1	"Continuity of Patient Care"[mh:noexp] OR "Transition to Adult Care"[mh] OR transition[tiab] OR transitions[tiab] OR transitioning[tiab] OR transitional[tiab]	247658
#2	care[tiab] OR "healthcare"[tiab] OR "Health Services"[mh] OR "Health Services Research"[mh] OR "Health Services Accessibility"[mh] OR "Health Services Needs and Demand"[mh] OR "health services"[tiab] OR "Health Planning"[mh:noexp] OR "Patient Care Planning"[mh] OR "pediatric to adult"[tiab] OR "child to adult"[tiab]	2141964
#3	Adolescent[mh] OR youth[tiab] OR Child[mh] OR pediatric[tiab] OR paediatric[tiab] OR child[tiab] OR children[tiab] OR adolescent[tiab] OR adolescents[tiab] OR adolescence[tiab] OR teen[tiab] OR teens[tiab] OR teenage[tiab] OR teenager[tiab] OR teenagers[tiab] OR "Child Health Services"[mh] OR "Adolescent Health Services"[mh] OR "young people"[tiab]	2594321
#4	Adult[mh] OR adult[tiab] OR adults[tiab] OR adulthood[tiab]	5690952
#5	"Chronic Disease"[mh] OR "special needs"[tiab] OR "special healthcare needs"[tiab] OR "special health care needs"[tiab] OR "special health needs"[tiab] OR "Disabled Children"[mh] OR disability[tiab] OR disabled[tiab] OR "YSHCN"[tiab] OR "CSHCN"[tiab] OR "chronic disease"[tiab] OR "chronic illness"[tiab] OR "chronic diseases"[tiab] OR "Mental Disorders"[mh] OR "mental illness"[tiab] OR "attention deficit"[tiab] OR depression[tiab] OR anxiety[tiab] OR "conduct disorders"[tiab] OR autism[tiab] OR autistic[tiab] OR Asperger[tiab] OR Asperger's[tiab] OR "pervasive development disorders"[tiab] OR "Developmental Disabilities"[mh] OR "developmental delay"[tiab] OR "developmental delays"[tiab] OR "Intellectual Disability"[mh] OR "intellectual disabilities"[tiab] OR "mental retardation"[tiab] OR "mentally retarded"[tiab] OR asthma[mh] OR asthma*[tiab] OR diabetes[tiab] OR diabetic[tiab] OR "Diabetes Mellitus"[mh] OR Epilepsy[mh] OR "seizure disorders"[tiab] OR "seizure disorder"[tiab] OR epilepsy[tiab] OR "Headache Disorders"[mh] OR migraine*[tiab] OR "Brain Injuries"[mh] OR "traumatic brain injury"[tiab] OR "traumatic brain injuries"[tiab] OR concussion*[tiab] OR "Heart Defects, Congenital"[mh] OR "congenital heart disease"[tiab] OR "congenital heart defects"[tiab] OR "Hematologic Diseases"[mh] OR "blood disorders"[tiab] OR "sickle cell"[tiab] OR anemia[tiab] OR "HIV"[tiab] OR "HIV Infections"[mh] OR "Organ Transplantation"[mh] OR "transplant recipients"[tiab] OR "Deafness"[mh] OR "Blindness"[mh] OR deaf[tiab] OR blind[tiab] OR "Cystic Fibrosis"[mh] OR "cystic fibrosis"[tiab] OR "Cerebral Palsy"[mh] OR "cerebral palsy"[tiab] OR "Muscular Dystrophies"[mh] OR "muscular dystrophy"[tiab] OR "Down Syndrome"[mh] OR "Joint Diseases"[mh] OR arthritis[tiab] OR "functional disability"[tiab] OR "functional disabilities"[tiab] OR "Congenital, Hereditary, and Neonatal Diseases and Abnormalities"[mh] OR "congenital disease"[tiab] OR "congenital diseases"[tiab] OR "congenital defects"[tiab] OR "spina bifida"[tiab] OR "Crohn Disease"[tiab] OR Crohn[tiab] OR "Celiac Disease"[mh] OR celiac[tiab] OR "genetic disease"[tiab] OR "genetic disorder"[tiab] OR "genetic disorders"[tiab] OR "genetic diseases"[tiab]	4049292
#6	#1 AND #2 AND #3 AND #4 AND #5 NOT (comment[pt] OR letter[pt] OR editorial[pt] OR news[pt] OR patient education handout[pt] OR legal cases[pt] OR newspaper article[pt] OR news[pt] OR historical article[pt] OR jsubsetk)	1878
#7	#6 AND English[la] AND humans[mh]	1656
#8	#7 AND ("2000/01/01"[dp] : "3000/12/31"[dp])	1373

Key: [tiab] title or abstract word; [th] therapy; [la] language; [mh] medical subject heading; [pt] publication type; "jsubsetk" consumer health journal subset

## Appendix B. Screening Forms

**Table B-1. Abstract Screening Form**

<b>Abstract Screening Form</b> <b>Technical Brief Transition Care for Children with Special Health Needs</b>			
First Author, Year: _____ Reference # _____			
Primary Inclusion/Exclusion Criteria			
1. Population is children (youth)	Yes	No	Cannot Determine
2. Population with special health need (excluding end of life, palliative care, and cancer)	Yes	No	Cannot Determine
3. Addresses transition care from pediatric to adult	Yes	No	Cannot Determine
4. Health care setting	Yes	No	Cannot Determine
5. Reports original research	Yes	No	Cannot Determine
6. Addresses a guiding question	Yes	No	Cannot Determine
<b>Retain for:</b> _____ BACKGROUND/DISCUSSION _____ REVIEW OF REFERENCES _____ Other _____			
<b>COMMENTS:</b>   			

**Table B-2. Full Text Screening Form**

<b>Full Text Screening Form</b> <b>Transition Care for Children with Special Health Needs</b>		
First Author, Year: _____ Reference # _____		
Inclusion/Exclusion Criteria		
1. Population is children (youth)	Yes	No
2. Population with special health need (exclude end of life, palliative care, cancer)	Yes	No
3. Addresses care transition from pediatric to adult	Yes	No
4. Healthcare setting	Yes	No
5. Reports original research	Yes	No
Addresses one or more of the following:  ____ GQ1a: What is the purpose of transition care and what are the theoretical advantages and disadvantages? ____ GQ1b: What are the common components of transition care interventions or processes used in clinical practice for children/adolescents with special healthcare needs? ____ GQ1c: How do currently used approaches to transitioning healthcare address the complexity of health issues including comorbidities and the presence of both physical and intellectual/developmental disabilities? ____ GQ2a: How widely available are programs or approaches to transition care within the healthcare setting for children/adolescents with special healthcare needs? ____ GQ2b: What are the resources needed to implement transition care? ____ GQ2c: What are the specific barriers to implementing transition care or processes for children/adolescents with special healthcare needs? ____ GQ2d: Who delivers transition interventions and what training is required to implement identified approaches to transition care for children/adolescents with special healthcare needs? ____ *GQ3a: What patient groups/clinical conditions are represented in studies on the use and evaluation of transition care for children/adolescents with special healthcare needs? ____ *GQ3b: What is the length of followup in studies on the use and evaluation of transition care for children/adolescents with special healthcare needs? ____ *GQ3c: What outcomes are measured in studies on the use and evaluation of transition care for children/adolescents with special healthcare needs? ____ GQ4a: What are the implications (e.g., ethical, privacy, economic) of the current level of diffusion and of further diffusion of transition care for children/adolescents with special healthcare needs? ____ GQ4b: What are possible areas of future research for transition care for children/adolescents with special healthcare needs and what research designs are appropriate to address these research topics? ____ Does not address a Guiding Question *Must be original research evaluation study		
<b>Retain for:</b> ____ <b>REVIEW OF REFERENCES</b> ____ <b>BACKGROUND/DISCUSSION</b> ____ <b>Other</b>		
<b>COMMENTS:</b>		

## Appendix C. Summary of Grey Literature

**Table C-1. Summary of Grey Literature- Internet Search Results**

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
Autism Transition Handbook: Health Care	Information on transition resources for individuals with autism spectrum disorder and links to state-level information.	Devereux Foundation	Autism		•	•				
Good2Go Transition Program	Program to prepare youth with chronic health conditions to leave the hospital by the age of 8 and use adult health care services successfully.	The Hospital for Sick Children	Chronic health condition		•	•			•	
The Adolescent Leadership Council (TALC)	Mentor program for chronically ill adolescents to prepare for transition to adulthood.	Hasbro Children's Hospital	Chronic health condition		•	•				
Taking Responsibility for Adolescent/Adult Care (ON TRAC)	Model of transition care for adolescents with chronic health conditions.	Children's and Women's Health Centre	Congenital heart disease			•	•		•	
Cystic Fibrosis	Structured transition	University of	Cystic fibrosis			•				

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
Transition Program	program.	Michigan								
Cystic Fibrosis Transition Program	Specialized service partners with patients family to facilitate transition to adult care.	Lurie Children's Memorial Hospital	Cystic fibrosis			•				
CART Model Programs	White paper discusses model programs for transition from childhood and adolescence to adult.	The Special Hope Foundation	Developmental disability			•	•			
Elizabeth M. Boggs Center on Developmental Disabilities	Developing a New Jersey Developmental Disabilities Transition to Adult Health Care Forum.	Rutgers Robert Wood Johnson Medical School	Developmental disability		•					
Florida Developmental Disabilities Council: Health Care Transition	Health care transition training modules, workbook, and other resources for young people with developmental disabilities.	Florida Developmental Disabilities Council	Developmental disability		•					
Moving from Pediatric to Adult Health Care, Healthy Transitions NY	Website developed for youth with developmental disabilities, family caregivers, service coordinators, and health care providers.	Golisano Children's Hospital, State University of New York Upstate Medical	Developmental disability		•	•		•		•

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
		University								
Special Hope Foundation	Foundation funds projects on delivery of health care to adults with developmental disabilities.	The Special Hope Foundation	Developmental disability		•					
Taking Charge of My Health: Partners in Transition	Special Hope Foundation funded project to develop and test training modules for parents of young adults with developmental disabilities through transition from pediatric to adult care.	Westchester Institute for Human Development	Developmental disability			•				
Tools for primary care providers	Provides a list of forms and tools to assist providers of adults with developmental disabilities.	Surrey Place Centre	Developmental disability				•			
The Maestro Project	A community resource and transition support service for young adults with type I and type II diabetes.	Department of Pediatrics and Child Health	Diabetes		•	•	•			
disability.gov	Federal government website catalogue of nationwide disability	U.S. Department of Labor	Disability		•					•

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
	programs and services.									
The Best Journey to Adult Life	Youth, family, and service providers identified best practices for transition to adulthood for youth with disabilities.	CanChild Centre for Childhood Disability Research, McMaster University	Disability	•		•	•			
Transition Planning for Adolescents with Special Health Care Needs: Information for Families and Teens	Booklet for youth transitioning to adulthood with a section on health care issues.	Institute for Community Inclusion, University of Massachusetts	Disability		•	•		•	•	
Transitioning Youth: Healthcare	Resources and tools to prepare youth with disabilities for health care transition.	Governor's Interagency Transition Council	Disability		•	•				•
Work Ability Utah: Transition to Adult Health Care	Resources for assessment and planning of health care transitions for youth with special health care needs.	Utah Department of Health	Disability		•	•			•	•
Consensus statement on the management of GH-treated adolescent in the transition to adult care	Consensus workshop summary of transition for growth hormone treated patients in transition from	European Society for Paediatric Endocrinology	Endocrine disease	•			•			



Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
	pediatric to adult care.									
Young Person Clinic	Special clinic with pediatric and adult endocrine teams	Royal Manchester Children's Hospital	Endocrine disease			•				
Adolescent Epilepsy Transition Clinic	Nurse led transition clinic within an epilepsy program.	University of Alberta Hospital	Epilepsy			•	•		•	
900 Clinic Transition Service	Specialty multidisciplinary clinic patients attend for 6-8 years.	Imperial College Healthcare NHS Trust	HIV			•				
Transition from CAMHS to adult mental health services (TRACK): a study of service organisation, policies, process and user and carer perspective	National Institutes for Health Research funded transition project on organizational and clinical determinants of effective transition from child and adolescent mental health services to adult psychiatric services.	University of Warwick	Mental health						•	
National Center for Medical Home Implementation: Transitions	Links to resources on appropriate care transitions, guidance documents, and opinion statements.	American Academy of Pediatrics	Not specified		•					
Transition to Adult	Information for	Great Ormond	Not specified			•	•	•	•	

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
Health Services	providers and patients transitioning to adult health care.	Street Hospital for Children								
Improving Sickie Cell Transitions of Care through Health Information Technology	Ongoing project to understand the needs of Sickie cell disease patients, caregivers, and providers and create a toolkit for Sickie cell disease care transitions.	National Initiative for Children's Healthcare Quality (NICHQ)	Sickie cell disease		•					
Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolescents with Sickie Cell Disease	Suggested topics, methods, and efficacy measurements and proposes steps for transitioning by age group with subsections on medical issues.	National Initiative for Children's Healthcare Quality (NICHQ)	Sickie cell disease	•			•			
Sickie Cell Disease Transition Program	Educational program coordinated by Child Life Specialist with didactic information, web-based and print resources.	Department of Pediatrics, Duke University	Sickie cell disease			•			•	
Sickie Cell Disease Treatment Demonstration Program	Ongoing project of quality improvement strategies for care of individuals with sickie cell disease.	National Initiative for Children's Healthcare Quality (NICHQ)	Sickie cell disease		•					

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
Adolescent Health Transition Project	Information, links, and material on transition from pediatric to adult health care for adolescents with special health care needs.	Center on Human Development and Disability, University of Washington	Special health need		•	•	•	•	•	
Adolescent Transition for People with Special Health Care Needs	Links to brochures summarizing transition, checklists for youth, and other resources.	Rhode Island Department of Health	Special health need			•	•	•	•	•
Catalyst Center: Youth Transition, Telemedicine and Other Capacity Building Services	Funded by Maternal and Child Health Bureau to support youth transition, telemedicine, and other capacity building services.	Catalyst Center, Boston University School of Public Health	Special health need		•					
Commission for Children with Special Health Care Needs: Transition Resources	Links to sites with information for helping young people with independence in health care	Kentucky Cabinet for Health and Family Services	Special health need		•					•
Creating Healthy Futures (CHF clinic)	Transition clinic for adolescents and young adults with special health needs.	Department of Nursing, University of Southern California	Special health need				•			

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
Got Transition? Center for Health Care Transition Improvement	Guidance and tools to aid in health care transitions for adolescents and young adults.	The National Alliance to Advance Adolescent Health	Special health need	•	•	•	•	•	•	
Health Transition Wisconsin	Web site with transition tools and links to additional resources for families and clinicians	Health Transition Wisconsin	Special health need		•	•	•			•
Healthy and Ready to Work, National Resource Center	Includes resources for understanding systems, access to quality health care, and increasing involvement of youth.	Maternal and Child Health Bureau	Special health need		•	•				•
Kentucky Youth Transitioning to Employment and Comprehensive Healthcare (KY TEACH)	Assist young people with special health care needs to find medical homes and employment with health insurance.	Kentucky Cabinet for Health and Family Services	Special health need		•	•			•	•
Navigating Health Care Transitions	Information about pilot project and tool for recommendations by age group and life domain.	Family Voices Colorado	Special health need			•				
Office for Genetics & Children with Special	Resource site for youth and providers,	Maryland Department of	Special health need		•	•	•			•

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
Health Care Needs: Health Care Transition	including an adult care notebook.	Health and Mental Hygiene								
Roadmap for Transitioning Adolescents from a Pediatric to an Adult Practice	Document developed by providers and parents to address transition from pediatric to adult care for patients with special health needs.	Children's Hospitals and Clinics of Minnesota	Special health need			•	•			
Special Medical Services: Health Care Transition	Description of planning process by the Specialized Medical Services and Health Care Transition Coalition to promote quality of care during the health care transition.	New Hampshire Department of Health and Human Services	Special health need	•		•	•	•		•
Tools for Transition	Educational resources for youth, a transition resource directory, and health care transition checklist.	Massachusetts Family Voices	Special health need		•					
Transition Age Youth	Transition planning for adolescents with special health care needs and disabilities.	Massachusetts Child Psychiatry Access Project	Special health need			•	•			
Transition Information and Resources for	Transition resources for youth with special	Louisiana Department of	Special health need		•					•

Resource Name	Description	Organization / Institution	Condition	Consensus / Guideline	Portal	Patient Material	Clinician Guide	Fact Sheet / Data	Assessment / Evaluation Tool	Government
Families and Youth	health care needs.	Health and Hospitals								
Transition Program	Provides support for medically complex patients ready to transition from pediatric to adult care.	Lurie Children's Memorial Hospital	Special health need		•	•	•	•		
Transition to Adult Health Care: A Training Guide in Two Parts	Workshop guide and materials for parents, and youth with special health care needs ready to transition to adult healthcare.	Waisman Center, University of Wisconsin Madison	Special health need			•		•		
Spina Bifida Transition Program	Describes processes, strategies, and tools to establish a transition program.	Children's Hospital of Wisconsin	Spina bifida				•			
				5	26	32	21	8	12	11

**Table C-2. Summary of Grey Literature- State and U.S. Resources**

<b>Title</b>	<b>Location</b>	<b>Description</b>	<b>Organization</b>	<b>URL</b>
Achieving the Outcomes for CSHCN	HI	Transition to Adult Health Care, Work, & Independence is a major outcome of focus; section links to original guides and workbooks	State of Hawaii, Department of Health, Children with Special Health Needs Branch	<a href="http://health.hawaii.gov/cshcn/cshcnoutcomes/">http://health.hawaii.gov/cshcn/cshcnoutcomes/</a>
Adolescent Services, Helping You Transition to Adulthood: Resources for New Jersey's Youth	NJ	Contains resource guides and outside resources for transitioning adolescents	New Jersey Department of Children and Families	<a href="http://www.nj.gov/dcf/adolescent/">http://www.nj.gov/dcf/adolescent/</a>
Adolescent Transition for People with Special Health Care Needs	RI	Links to brochures summarizing transition, checklists for youth, Youth transition workbook (with section on healthcare advocacy), and other resources	State of Rhode Island Department of Health	<a href="http://www.health.ri.gov/specialhealthcareneeds/about/adolescenttransition/">http://www.health.ri.gov/specialhealthcareneeds/about/adolescenttransition/</a>
Carolina Health and Transition (CHAT): A Guide to Transition from Pediatric to Adult Health Care	NC	Handbook for transitioning from pediatric to adult care	North Carolina Division of Public Health: Women's and Children's Health: Children and Youth	<a href="http://www.ncdhhs.gov/dph/wch/doc/lhd/CHAT/Youth_Guide_12-09.pdf">http://www.ncdhhs.gov/dph/wch/doc/lhd/CHAT/Youth_Guide_12-09.pdf</a>
Commission for Children with Special Health Care Needs: Transition Resources	KY	Assist young people with special healthcare needs to find medical homes and employment with health insurance; create system changes that promote smooth transitions from school to work and from pediatric to adult healthcare; links to sites with information for helping young people with independence in health care.	Commission for Children with Special Health Care Needs, Kentucky Cabinet for Health and Family Services	<a href="http://chfs.ky.gov/ccshcn/ccshcntransition.htm">http://chfs.ky.gov/ccshcn/ccshcntransition.htm</a>
Continuum of Care	SC	Handbooks and manuals for transitioning to adulthood, with sections on health	Governor's Office of Executive Policy and Programs	<a href="http://www.oepp.sc.gov/coc/default.html">http://www.oepp.sc.gov/coc/default.html</a>
CSH Healthcare Transitioning	WY	Suggestions and resources for transitioning to adult health services	Wyoming Department of Health	<a href="http://www.health.wyo.gov/familyhealth/csh/transitions.html">http://www.health.wyo.gov/familyhealth/csh/transitions.html</a>
DMH Transitional Age Youth Initiative	MA	Links to Young Adult Resource Guide with a section on health	Massachusetts Department of Mental Health	<a href="http://www.mass.gov/eohhs/gov/departments/dmh/transitional-age-youth-initiative.html">http://www.mass.gov/eohhs/gov/departments/dmh/transitional-age-youth-initiative.html</a>
Health Care Program for Children with Special Needs (HCP)	CO	Page has a section that links to transition to adult health care resources - some created by state, some external	Colorado Department of Public Health and Environment	<a href="http://www.colorado.gov/cs/Satellite/CDPHE-PSD/CBON/1251617590646">http://www.colorado.gov/cs/Satellite/CDPHE-PSD/CBON/1251617590646</a>
Health Transition Wisconsin	WI	Web site with transition tools including videos, a checklist, and pocket guide, and links to additional resources for families and clinicians	Wisconsin Regional Centers, Children and Youth with Special Health Care Needs	<a href="http://www.healthtransitionwi.org/">http://www.healthtransitionwi.org/</a>

Title	Location	Description	Organization	URL
Healthy and Ready to Work, National Resource Center	US	Website for a project that has ended, but includes resources for understanding systems, access to quality health care, and increasing involvement of youth.	Maternal and Child Health Bureau	<a href="http://www.syntiro.org/hrtw/">http://www.syntiro.org/hrtw/</a>
Independent Living Program	NV	Program with resources to prepare foster youth to transition to adulthood; medical care is one topic	Nevada Division of Child and Family Services	<a href="http://www.dcfs.state.nv.us/dcfs_independentlyliving.htm">http://www.dcfs.state.nv.us/dcfs_independentlyliving.htm</a>
Now that you're in high school... it's time to be more in charge of your health	FL	Booklet directs teens with SHN to be more in charge of their health care, focusing on both teens and the transition to adulthood	Florida Department of Health and University of FL	<a href="http://www.floridahealth.gov/alternatesites/cms-kids/kids_teens/documents/high_school_booklet.pdf">http://www.floridahealth.gov/alternatesites/cms-kids/kids_teens/documents/high_school_booklet.pdf</a>
Office for Genetics & Children with Special Health Care Needs: Health Care Transition	MD	Office For Genetics And People With Special Health Care Needs resource site for youth and providers, including an adult care notebook	Maryland Department of Health and Mental Hygiene	<a href="http://phpa.dhmdh.maryland.gov/genetics/SitePages/Health_Care_Transition.aspx">http://phpa.dhmdh.maryland.gov/genetics/SitePages/Health_Care_Transition.aspx</a>
Oklahoma Healthy Transitions Initiative	OK	Initiative to establish consortium of statewide community-based services for transitioning youth; also has resource guides	Oklahoma Department of Mental Health and Substance Abuse Services	<a href="http://ok.gov/odmhsas/Mental_Health/Children,_Youth,_and_Family_Services/Systems_of_Care/Oklahoma_Healthy_Transitions_Initiative_%28OHTI%29/">http://ok.gov/odmhsas/Mental_Health/Children,_Youth,_and_Family_Services/Systems_of_Care/Oklahoma_Healthy_Transitions_Initiative_%28OHTI%29/</a>
Special Education and Support Services: Secondary Transition	IL	Links to healthcare related webinar	Illinois State Board of Education	<a href="http://www.isbe.state.il.us/spec-ed/html/total.htm">http://www.isbe.state.il.us/spec-ed/html/total.htm</a>
Special Medical Services: Health Care Transition	NH	Description of planning process by the Specialized Medical Services and Health Care Transition Coalition to promote quality of care during the health care transition from adolescent to adult, including transition checklist and timeline for providers and other tools	New Hampshire Department of Health and Human Services	<a href="http://www.dhhs.state.nh.us/dcbcs/bds/sms/transition.htm">http://www.dhhs.state.nh.us/dcbcs/bds/sms/transition.htm</a>
Systems in Sync: Transition to Adulthood	KS	Project focusing on guiding young adults with SHN through the transition to adulthood, specifically integrating health transition with work, education, and independent living.	Kansas Department of Health and Environment	<a href="http://www.systemsinsync.org/goals_transition.htm">http://www.systemsinsync.org/goals_transition.htm</a>
Transition for Young Adults	DE	Page contains facts, principles, and local resources for transitioning	Healthy Delawareans with Disabilities	<a href="http://www.gohdwd.org/health-care/transition-for-young-adults/">http://www.gohdwd.org/health-care/transition-for-young-adults/</a>
Transition Guides	ID	Interactive guides to health care transition separated by age groups	Idaho Department of Health and Welfare	<a href="http://www.healthandwelfare.idaho.gov/Children/ChildrensSpecialHealthProgram/HealthCareTransitiontoAdulthood/tabid/1472/D">http://www.healthandwelfare.idaho.gov/Children/ChildrensSpecialHealthProgram/HealthCareTransitiontoAdulthood/tabid/1472/D</a>



Title	Location	Description	Organization	URL
				efault.aspx
Transition Health Care Checklist: Transition to Adult Living in Pennsylvania	PA	Checklist, resources, steps to assist youth and families in transitioning to adult health and health care	Pennsylvania Department of Health	<a href="http://www.portal.state.pa.us/portal/server.pt/community/special_kids_network/14205/transition_health_care_checklist/558090">http://www.portal.state.pa.us/portal/server.pt/community/special_kids_network/14205/transition_health_care_checklist/558090</a>
Transition Information	TX	Information and links to resources for patients, patient families, and providers on transition of youth with special health needs from pediatric to adult care.	Texas Department of State Health Services	<a href="http://www.dshs.state.tx.us/cshcn/transinfo.shtm">http://www.dshs.state.tx.us/cshcn/transinfo.shtm</a>
Transition Information and Resources for Families and Youth	LA	Transition resources for youth with special health care needs, including a guide to family involvement and resources by state region	Louisiana Department of Health and Hospitals	<a href="http://dhh.louisiana.gov/index.cfm/page/1137">http://dhh.louisiana.gov/index.cfm/page/1137</a>
Transition Information Packet	IA	Booklet on transition for youth exiting the foster care system, with a section on health	Iowa Department of Human Services	<a href="http://www.dhs.iowa.gov/Consumers/Child_Welfare/Transition_Services/Transitioning%20to%20Adulthood.html">http://www.dhs.iowa.gov/Consumers/Child_Welfare/Transition_Services/Transitioning%20to%20Adulthood.html</a>
Transition Issues	OH	Links to a document on medical transition	Ohio Department of Health	<a href="http://www.odh.ohio.gov/odhprograms/cmhc/cwmh/infomam/cmhmtrn.aspx">http://www.odh.ohio.gov/odhprograms/cmhc/cwmh/infomam/cmhmtrn.aspx</a>
Transition Resources	MT	Page of outside health care transition resources	Montana Department of Public Health and Human Services	<a href="http://www.dphhs.mt.gov/publichealth/cshs/transitionresources.shtml">http://www.dphhs.mt.gov/publichealth/cshs/transitionresources.shtml</a>
Transition to Adulthood	MI	Page contains original guides and resource manuals for health care transition	Michigan Department of Community Health	<a href="http://www.michigan.gov/mdch/0,4612,7-132-2942_4911_35698-135030--,00.html">http://www.michigan.gov/mdch/0,4612,7-132-2942_4911_35698-135030--,00.html</a>
Transition to Adulthood	ND	Page has a section that links to external pediatric to adult health resources	North Dakota Department of Health, Children's Special Health Services	<a href="http://www.ndhealth.gov/cshs/TransitionToAdulthood.htm">http://www.ndhealth.gov/cshs/TransitionToAdulthood.htm</a>
Transitioning Youth: Healthcare	MD	Resources and tools to prepare youth with disabilities for health care transition	State of Maryland (collaboration of many departments)	<a href="http://www.mdtransition.org/Health%20Care.htm">http://www.mdtransition.org/Health%20Care.htm</a>
Work Ability Utah: Transition to Adult Health Care	UT	Resources for assessing current status and planning health care transitions for youth with special health care needs	Utah Department of Health	<a href="http://www.workabilityutah.org/community/healthy/transitionhealthcare.php">http://www.workabilityutah.org/community/healthy/transitionhealthcare.php</a>
Young Adults in Transition	OR	Links to a few resources for young adults in transition	Oregon Department of Human Services, Addiction and Mental Health Services	<a href="http://www.oregon.gov/oha/amh/pages/child-mh-soc-in-plan-grp/main.aspx#young">http://www.oregon.gov/oha/amh/pages/child-mh-soc-in-plan-grp/main.aspx#young</a>
Young Adults Transition	WA	Designed to guide youth towards adult life and	Washington State Department	<a href="http://here.doh.wa.gov/materials">http://here.doh.wa.gov/materials</a>

<b>Title</b>	<b>Location</b>	<b>Description</b>	<b>Organization</b>	<b>URL</b>
Plan: Your Future / Your Life		additional responsibility in healthcare	of Health	/transition-plan-young-adults/13_CSHCN-18yr_E11L.pdf
Youth and Transition Services	MN	Resources for transitioning youth with mental health needs	Minnesota Department of Human Services	<a href="http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNA MIC_CONVERSION&amp;RevisionS electionMethod=LatestReleased&amp;dDocName=dhs16_167209">http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNA MIC_CONVERSION&amp;RevisionS electionMethod=LatestReleased&amp;dDocName=dhs16_167209</a>
Youth in Transition Grant	VT	Project to support youth transitioning to adulthood through community supports, events, resources - access to a medical home is one of the desired outcomes	Vermont Department of mental Health	<a href="http://www.youth-in-transition-grant.com/">http://www.youth-in-transition-grant.com/</a>
Youth in Transition to Adulthood	TN	Links to a few resources and programs for transitioning youth, some for health and mental health	Tennessee Division of Mental Health Services	<a href="http://tn.gov/mental/children/child_youth_adult.shtml">http://tn.gov/mental/children/child_youth_adult.shtml</a>
Youth Transitions, Office for Children with Special Health Care Needs	AZ	Page on government website that links to health transition resources	Arizona Department of Health Services	<a href="http://www.azdhs.gov/phs/owch/ocshcn/youth-transition.htm">http://www.azdhs.gov/phs/owch/ocshcn/youth-transition.htm</a>
Youth with Special Health Care Needs	CT	Page contains some original resources on transitioning to adult health care (for young adults, parents, and providers) and links to some external resources	Connecticut Department of Public Health	<a href="http://www.ct.gov/dph/cwp/view.asp?a=3138&amp;q=432684">http://www.ct.gov/dph/cwp/view.asp?a=3138&amp;q=432684</a>

**Table C-3. Summary of Grey Literature- Transition Care Consensus Statements**

<b>Author/ Organization(s) , year Title</b>  <b>Country</b>	<b>Brief description</b>
American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine, 2002 <sup>1</sup> A consensus statement on health care transitions for young adults with special health care needs  United States	Critical first steps that the medical profession needs to take to realize the vision of a family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent health care system.
Clayton et al., 2005 <sup>2</sup> Consensus statement on the management of the GH-treated adolescent in the transition to adult care. European Society of Paediatric Endocrinology Consensus Development Conference  England	Summary of discussions at a consensus workshop related to issues in caring for GH-treated patients in the transition from pediatric to adult life.
Nutt et al., 2007 <sup>3</sup> Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology  England	Consensus conference to review the body of evidence on childhood ADHD and the growing literature on ADHD in older age groups. Much of this initial guidance on managing ADHD in adolescents in transition and in adults is based on expert opinion derived from childhood evidence.
Peters and Laffel, 2011 <sup>4</sup> Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association  United States	Consensus statement provides a framework for health care delivery during the transition period and an agenda for future research for youth and young adults with diabetes and their health care providers.
Watson et al., 2011 <sup>5</sup> Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA)  United States	Consensus statement developed by the panel of adult and pediatric nephrologists.
Webb et al., 2010 <sup>6</sup> Building consensus on transition of transplant patients from paediatric to adult healthcare  England	Seven consensus statements representative of the current opinion of families and the UK transplant community.

**Table C-4. Summary of Grey Literature Selected Transition Programs**

<b>Citation Location</b>	<b>Model</b>	<b>Population</b>	<b>Setting</b>	<b>Description</b>
Jurasek et al., 2010 <sup>7</sup> Edmonton, Canada **	<b>Adolescent Epilepsy Transition Clinic</b>	Epilepsy	University of Alberta Hospital	Nurse-led transition clinic within comprehensive epilepsy program
Kripke et al., 2011 <sup>8</sup> California, U.S.	<b>CART model program</b>	Developmental disability	Administered by public health insurance plan	Includes medical home, center of excellence, and health advocacy services
Betz and Redcay, 2003 <sup>9</sup> California, U.S.	<b>Creating Healthy Futures</b>	Special health care needs	Department of Nursing Clinic, University of Southern California	Family nurse practitioner, interagency team of child and adult providers
Amara et al., 2011 <sup>10</sup> Toronto, ON, Canada	<b>Good2Go Transition Program</b>	Chronic health conditions	The Hospital for Sick Children	Preparation for youth with chronic health conditions to leave the hospital and use adult healthcare services successfully
Paone, et al., 2006 <sup>11</sup> British Columbia	<b>ON TRAC</b>	Pediatric transplant	Children's and Women's Health Care Centre	Developmentally appropriate (based upon adolescent development) teaching including tasks and skills and a care pathway to outline management practice and quality transitional care.
Kaufmann Rauen et al., 2013 <sup>12</sup> Wisconsin, U.S.	<b>Spina Bifida Transition Program</b>	Spina bifida	Children's hospital	Partnership between pediatric and adult providers, guided by the Transition Care Model and the Ecological Model of Secondary Conditions and Adaptation
Stewart, et al. 2009 <sup>13</sup> Hamilton, ON, Canada	<b>The Best Journey to Adult Life</b>	Developmental disability	CanChild Centre for Childhood Disability Research, McMaster University	Best practices for the transition to adulthood for youth with disabilities
Smith et al., 2011 <sup>14</sup> North Carolina, U.S.	<b>Sickle Cell Disease Transition</b>	Sickle cell disease	Duke Department of Pediatrics	Coordinated by a child life specialist
Vanelli et al., 2004 <sup>15</sup> **	<b>Parma protocol</b>	Adolescents with type 1 diabetes	Pediatric, adult specialty clinic  Pediatric and adult providers	Protocol for an uninterrupted procedure for transfer including introduction to the adult provider prior to transition and attendance by the pediatrician at the first adult visit. Transition occurred when the patient and parents agreed
Chaudhry et al., 2013 <sup>16</sup> Michigan, U.S. **	<b>Structured transition program</b>	Adults with cystic fibrosis	Academic medical center	Structured transition program beginning early in adolescence, focusing on developing independence. Included a transition coordinator and participation of the adult

Citation Location	Model	Population	Setting	Description
				pulmonologist in the pediatric clinic until readiness is achieved.
Gerber et al., 2007 <sup>17</sup> Illinois, US	<b>STYLE</b>	Young adults with diabetes	Inner-city clinics and childhood diabetes registry  Diabetes educator	Internet-based transition program including information on DM, goal-setting exercises with feedback, role-playing, empowerment and communication skills
Maslow et al., 2012 <sup>18</sup> Rhode Island, U.S. **	<b>The Adolescent Leadership Council (TALC)</b>	Individuals with a chronic illness aged 13-19 years	Hasbro Children's hospital  Pediatric and psychiatry residents, child life therapists, medical students, supervised by pediatric and psychiatry attending physicians	10-month group mentoring program based on the Positive Youth Development framework
Van Wallegghem et al., 2006 <sup>19</sup> and 2008 <sup>20</sup> Manitoba, Canada **	<b>The Maestro Project</b>	Youth with type 1 diabetes aged under 18 years	Community clinics, diabetes education resource center	Systems navigator model, administrative coordinator maintains phone and email contact with patients to identify barriers. Delivery methods include a comprehensive website, a bimonthly newsletter, a drop-in group and educational events
Hankins et al., 2012 <sup>21</sup> Tennessee, U.S. **	<b>Transition Pilot Program</b>	Youth with sickle cell disease aged 17-19 years	Pediatric hospital  Pediatric hematology staff	Transition Pilot Program including a tour of adult SCD programs, lunch discussion with pediatric staff and scheduling of the first adult visit by the pediatric hematology case manager
Chaturvedi et al., 2009 <sup>22</sup> Australia **	<b>Transition program</b>	Pediatric kidney transplant recipients	Children's hospital renal clinic  Transition coordinator, transition adult nephrologist, and transition nurse	Transition clinic, development of self-management skills and a written transition summary
Craig et al., 2007 <sup>23</sup> Australia	<b>Transition program</b>	Youth with cystic fibrosis	Children's hospital	Phase-based transition program, including a preparation phase in early adolescence and an active phase that begins around age 16.
Byron and Madge, 2001 <sup>24</sup>	<b>Transition Programme</b>	Youth with cystic fibrosis	Children's hospital	
Price et al., 2011 <sup>25</sup> UK	<b>Transitions Pathway model</b>	Youth with type 1 diabetes aged 16-18 years	Hospital	Transitions Pathway model including 4 preparatory visits leading up to transfer to the 16 – 25 year old clinic focusing on fitting diabetes care into current and future life and ensuring that patients received adequate

Citation Location	Model	Population	Setting	Description
				advice. Upon request, pediatrician attended first visit in the young adult clinic.
Gleeson et al., 2013 <sup>26</sup> UK **	<b>Young Person Clinic</b>	Individuals with congenital adrenal hyperplasia	Children's hospital  Pediatric and adult endocrine teams	Young Person Clinic (YPC) at which the youth is introduced to an adult endocrinologist
Bent et al., 2002 <sup>27</sup> UK **	<b>Young Adult Teams</b>	Youth with long-term physical disability	4 regions	Young Adult Teams, including multidisciplinary teams including a consultant in rehabilitation medicine, a psychologist, therapists and a social worker

\* also in the transition program evaluation table in GQ3

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## Appendix D. Reasons for Exclusion

Exclusion Code	Exclusion Reason	Count
<b>X-1</b>	Not youth	10
<b>X-2</b>	Population does not have a special health need	4
<b>X-3</b>	Publication did not address transition from pediatric to adult health care	60
<b>X-4</b>	Not a health care setting	27
<b>X-5</b>	Not original research and does not address a guiding question	55
<b>X-6</b>	Original research does not address a guiding question	85
<b>X-7</b>	Unavailable	2

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## Appendix E. Ongoing Studies

Study Name Location Trial Identifier	Study Status	Population Disease/Condition Age	Interventions / Groups	Primary Outcome Measures
Transition of Adolescents and Young Adults with Diabetes from Pediatric to Adult Care  University of Kansas Medical Center Research Institute NCT01109797	Completed, results not published  Start: April 2010 Complete: May 2012	<ul style="list-style-type: none"> <li>• Type I Diabetes or type 2 diabetes managed with insulin</li> <li>• Age 16-29</li> </ul>	<b>Behavioral:</b> Transition Social Behavioral Intervention  <b>Behavioral:</b> Diabetes Transition Clinic	<ul style="list-style-type: none"> <li>• change in self-efficacy</li> <li>• change in diabetes knowledge diabetes quality of life</li> <li>• family conflict</li> <li>• treatment satisfaction</li> </ul>
Diabetes Care Management Compared to Standard Diabetes Care in Adolescents and Young Adults with Type 1 Diabetes (TransClin)  University of Western Ontario, Canada NCT01351857	Recruiting  Start: April 2012 Complete: December 2016	<ul style="list-style-type: none"> <li>• T1D diagnosis</li> <li>• Age 17-20</li> </ul>	<b>Other:</b> Transition Coordinator	<ul style="list-style-type: none"> <li>• change in one outpatient adult endocrinology visit</li> </ul>
Primary Care Transition Study  Children's Hospital of Philadelphia NCT01750892	Enrolling by invitation  Start: October 2012 Complete: December 2013	<ul style="list-style-type: none"> <li>• 1 chronic condition and/or cognitive disability</li> <li>• Age 19 or older</li> </ul>	<b>Behavioral:</b> REACH for Independence  <b>Behavioral:</b> Transition Consult <b>Other:</b> Study Materials	<ul style="list-style-type: none"> <li>• Successful transition to an adult provider</li> </ul>
Adolescent, Caregiver, and Young Adult Perspectives of the Transition from Pediatric to Adult Care for Sickle Cell Disease: A Preliminary Evaluation of the Sickle Cell Disease Transition Program  St. Jude Children's Research Hospital NCT01569971	Recruiting  Start: March 2012 Complete: September 2013	<ul style="list-style-type: none"> <li>• Adolescents with SCD</li> <li>• Young Adults with SCD</li> <li>• Age 12-30</li> </ul>	<b>Other:</b> Assessment (focus groups and questionnaires)	<ul style="list-style-type: none"> <li>• Grounded theory qualitative analysis of data</li> </ul>
The LETS Study: A Longitudinal Evaluation of Transition Services	Active, not recruiting  Start:	<ul style="list-style-type: none"> <li>• Diagnosis of cerebral palsy or acquired brain injury</li> </ul>	<b>Other:</b> Prospective LIFESpan <b>Other:</b> Prospective Non-LIFESpan	<ul style="list-style-type: none"> <li>• Maintenance of continuous care</li> </ul>

Study Name Location Trial Identifier	Study Status	Population Disease/Condition Age	Interventions / Groups	Primary Outcome Measures
Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario, Canada NCT00975338	September 2009 Complete: September 2013	<ul style="list-style-type: none"> <li>• Diagnosis of spina bifida</li> <li>• Age 16-23</li> </ul>	<b>Other:</b> Retrospective Non-LIFEsan	
Congenital Heart Adolescents: Program of Transition Evaluation Research (CHAPTER)  University of Alberta NCT01286480	Active, not recruiting  Start: January 2011 Complete: December 2012	<ul style="list-style-type: none"> <li>• Moderate or complex congenital heart disease or acquired heart disease</li> <li>• Age 15-17</li> </ul>	<b>Behavioral:</b> Clinic-based Educational Intervention	<ul style="list-style-type: none"> <li>• change in patient satisfaction questionnaire (PSQ-18)</li> <li>• change in parent/guardian Patient Satisfaction Questionnaire (PSQ-18)</li> <li>• change in patient knowledge of his/her CHD (MyHeart score)</li> </ul>
The CHAPTER II Study-Congenital Heart Adolescents Participating in Transition Evaluation Research  University of Alberta NCT01723332	Recruiting  Start: November 2012 Complete: May 2015	<ul style="list-style-type: none"> <li>• Moderate or complex CHD</li> <li>• Age 16-17</li> </ul>	<b>Behavioral:</b> Educational  <b>Behavioral:</b> Self-management	<ul style="list-style-type: none"> <li>• Excess time to first ACHD clinic appointment</li> </ul>
Transition Study of Inflammatory Bowel Disease (IBD) Patients from Pediatric Gastroenterologist to Adult Gastroenterologist  Vanderbilt University NCT00360022	Unknown  Start: August 2006 Complete: December 2012	<ul style="list-style-type: none"> <li>• Confirmed diagnosis of IBD</li> <li>• Age 16 and older</li> </ul>	<b>Other:</b> Transition program	<ul style="list-style-type: none"> <li>• Decrease IBD flare at 1 year</li> </ul>
Implementation of a Pediatric-to-Adult Asthma Transition Program  University of Calgary NCT01521247	Recruiting  Start: April 2010 Complete: December 2013	<ul style="list-style-type: none"> <li>• Clinical diagnosis of asthma</li> <li>• Age 17-19</li> </ul>	<b>Other:</b> Asthma Transition Program	<ul style="list-style-type: none"> <li>• Asthma Quality of Life Questionnaire with Standardized Activities</li> </ul>
Internet-based Educational Program to Promote Self- Management for Teens with Hemophilia  The Hospital for	Completed  Start: November 2011 Complete: March 2013	<ul style="list-style-type: none"> <li>• Diagnosis of mild, moderate or severe hemophilia A or B</li> <li>• Age 13-18</li> </ul>	<b>Other:</b> Teens Taking Charge: Managing Hemophilia Online-Online self-management intervention	<ul style="list-style-type: none"> <li>• Disease-specific knowledge gained</li> </ul>

Study Name Location Trial Identifier	Study Status	Population Disease/Condition Age	Interventions / Groups	Primary Outcome Measures
Sick Children NCT01477437				
Long-term Survival with HIV: Psychological and Behavioral Factors Associated with the Transition from Adolescence to Young Adulthood	Completed  Start: July 2001 Complete: June 2005	<ul style="list-style-type: none"> <li>• HIV-infected adolescents</li> <li>• Age 13-24</li> </ul>	NA	<ul style="list-style-type: none"> <li>• NA</li> </ul>
National Cancer Institute NCT00026806				
Health literacy- disparities and transition in teens with special healthcare needs	Ongoing  Start: September 2011 End: July 2016	<ul style="list-style-type: none"> <li>• Special healthcare need</li> <li>• Age 15-17</li> </ul>	NA	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Research Institute Nationwide Children's Hospital Medicaid managed plan in Southwest Ohio 5R01MD007160- 03				
Outcomes after transfer of pediatric renal transplant patients to adult providers	Completed  Start: August 2009 End: May 2011	<ul style="list-style-type: none"> <li>• Kidney transplant recipients</li> <li>• Ages 16-25</li> </ul>	NA	<ul style="list-style-type: none"> <li>• NA</li> </ul>
University of Virginia 5F31NR011237-02				
From adolescence to adulthood: persons with and without diabetes	Ongoing  Start: July 2013 End: June 2017	<ul style="list-style-type: none"> <li>• Diabetes</li> <li>• Ages 22-24</li> </ul>	NA	<ul style="list-style-type: none"> <li>• NA</li> </ul>
Carnegie-Mellon University 5R01DK060586-12				
Transitioning from childhood to adulthood: the impact of perinatal HIV infection	Ongoing  Start: December 2012 End: November 2013	<ul style="list-style-type: none"> <li>• Perinatally HIV infected youth</li> <li>• Perinatally HIV exposed, uninfected youth</li> </ul>	NA	<ul style="list-style-type: none"> <li>• NA</li> </ul>
New York State Psychiatric Institute 5R01MH069133- 10				
Barriers & facilitators to health	Ongoing	<ul style="list-style-type: none"> <li>• Youth and young adults complex</li> </ul>	NA	<ul style="list-style-type: none"> <li>• NA</li> </ul>

Study Name Location Trial Identifier	Study Status	Population Disease/Condition Age	Interventions / Groups	Primary Outcome Measures
care: transitioning youth with special needs  Okumura, Megie University of California, San Francisco AHRQ 5K08HS017716-05 HSRP20084171	Start: September 2012 End: September 2013	chronic conditions		
Cystic fibrosis as a model of health care transition for chronically ill youth  Children's Hospital Corporation 5K23HL105541-03	Ongoing  Start: July 2012 End: June 2016	• Adolescents and young adults with cystic fibrosis	NA	• NA
Patient-provider interventions to improve transition to adult care in SCD  Cincinnati Children's Hospital Medical Center 5K07HL108720-03	Ongoing  Start: August 2013 End: July 2015	• Sickle Cell Disease • Ages 16-24	NA	• NA
A health care transition randomized trial for minority youth with special health care needs  Tuchman, Lisa HRSA and MCHB HSRP20123116	Ongoing through 2015	• Not specified	Not specified	• Not specified
Service transitions among youth with autism spectrum disorders  Shattuck, Paul NIMH HSRP20102263	Ongoing through 2014	• Autism spectrum disorder	Not specified	• Not specified
Youth with complex needs: transition to adulthood plans  Rehm, Roberta S NICHD HSRP20102257	Completed 2012	• Complex chronic conditions	Not specified	• Not specified
Developmental	Ongoing	• Developmental	NA	• NA

<b>Study Name Location Trial Identifier</b>	<b>Study Status</b>	<b>Population Disease/Condition Age</b>	<b>Interventions / Groups</b>	<b>Primary Outcome Measures</b>
Disabilities Health Care E-Toolkit		disability		
McMillan, Elise Special Hope Foundation				